Brief Report

What Is Asthma Control? Discrepancies Between Parents' Perceptions and Official Definitions

Ann Dozier, C. Andrew Aligne, Mary Beth Schlabach

ABSTRACT: *National guidelines define asthma control as the prevention of asthma symptoms rather than the treatment of asthma exacerbations. We hypothesized that we would find a discrepancy between what parents consider adequate control compared to what health care professionals mean by "control." Data from a telephone survey conducted for the local asthma coalition served to establish a baseline measurement of community-level control of asthma among children. The sample consisted of 352 parents from the Rochester City School District, New York. Data analyses included chi-square, relative risk, and reliability statistics (kappa) to examine associations between reported asthma symptoms and parental perception of asthma control. Ninety percent of respondents indicated that the child was well or completely controlled even though over 50% of the children had missed school, experienced asthma symptoms, made an unscheduled office visit, or used an inhaler for symptom relief. Over 40% of those reporting good control still used a rescue inhaler for symptom relief, experienced symptoms, and missed school. Forty-two percent of children had parents whose report of symptoms was discrepant with their assessment of control. These children were at a higher risk of poor control compared to families whose responses were consistent. Parents of children with asthma thought their children's asthma was under good control despite high asthma-related morbidity. This discrepancy suggests a communication gap between health care providers and families that may contribute to underutilization of effective asthma treatments. These results have been used to focus our community interventions on increasing public awareness of the possibility of living symptom free with asthma and on increasing effective communication between families and physicians regarding the meaning of adequate asthma control.* (J Sch Health. 2006;76(6):215-218)

INTRODUCTION

As a leading chronic illness in children and a major cause of school absences,[1] asthma is recognized as a major school health issue.[2,3] Although not curable, it can be controlled. Control allows the individual to (1) be fully active and participate in physical education, (2) sleep through the night, (3) attend school or work every day, and (4) avoid emergency room visits and hospitalizations.[1] Despite the availability of effective treatment, many children receive suboptimal care, and their asthma is not under control.[4]

The Finger Lakes Regional Community Asthma Network (RCAN) strives to increase the percentage of children with asthma who are in good control. Through its inclusive approach, RCAN links parents, schools, community groups, and health care professionals. RCAN focused its initial efforts on the Rochester City School District (RCSD; 60,000 students) because of the high prevalence and severity of asthma among its students.[5] To document its overall community-level impact, RCAN sponsored a baseline community survey[1] of parents of children with asthma covering myriad topics including parents' awareness and definitions of asthma control. Based on previous experiences, we hypothesized that we would find a discrepancy between what parents considered to be adequate control versus what doctors and nurses mean by "control."

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METHOD

Population

Households with children diagnosed with asthma were identified through the RCSD's current-year health database (children greater than 5 years old with inhalers/asthma medication on file).

A random sample (n = 2068) stratified across 3 age groups was drawn from a deidentified school district list (3000 asthma-affected households). Trained telephone interviewers completed the survey over a 4-week period in early 2003, calling during daytimes, evenings, weekdays, and weekends. Of the 1235 calls attempted, 6% refused, 30% indicated no child with asthma, and 25% were inoperative telephone numbers.

Instrument

A 27-item telephone survey instrument used questions derived from national surveys (National Health and Nutrition Examination Survey [NHANES] III; Children and Asthma in America)[4] grouped into the following categories: (1) asthma-related health services/programs (9 items), (2) activity limitations (2 items), (3) presence of symptoms (2 items), (4) asthma medications (5 items), (5) parental perception of asthma control (1 item), (6) parental

confidence in asthma management (1), and (7) demographics (8 items). *Control* was measured through parent-reported, asthma-related hospitalizations; emergency room visits; urgent medical visits; activity restrictions; missing school; and sleeping through the night. Parental *perceptions* of control were assessed through reporting how well the child's asthma was controlled (completely/well/somewhat/poorly).

Sample Size

A sample size of 100 per age group (5-7, 8-11, and 12-18) would allow detection of a 20% change from the baseline survey findings (reported here) over a future readministration of the same survey. For the analyses reported herein, 350 subjects allowed us to detect between-group differences of 15% (0.80 power). For our analyses involving parental perceived control reported herein, 325 subjects could detect a between-group difference of 18% (0.90 power).

Analysis

Using chi-square on SPSS v12.0 for Windows (SPSS, Inc, Chicago, IL), we analyzed parents' perception of control in relation to reported symptoms, as well as other indicators of asthma control (rescue inhaler use). Follow-up analyses also calculated relative risk and a reliability measure (kappa statistic) to determine whether parents' perceptions of asthma control were consistent or discrepant with report of child's symptoms.

Human Subjects Protection

This study was reviewed and approved by the University of Rochester Institutional Review Board.

RESULTS

Demographics

A total of 357 parents or guardians (75% mothers) of children with asthma completed the survey. Mean age of parent/guardian was 40 years; 40% of households included a smoker. Of the children (average age 11 years), nearly 50% were diagnosed with asthma before 2 years of age and 25% by 5 years of age, and virtually all (99%) had a medical home (regular site of care) and health insurance; nearly 75% had government-provided or subsidized insurance.

Outcomes

During the 12 months preceding the survey, the children experienced the following problems as a result of their asthma: 53% of the children missed school; 43% limited their activity; 25% visited an emergency room at least once; and 40% had unscheduled visits to the doctor's office. During the 4 weeks prior to the survey, 35% reported awakening during the night with symptoms and 62% reported using a rescue inhaler for symptoms. Virtually every child (99%) used some medication. Based on the name(s) of the medication(s) provided, 37% of the children had a maintenance medication, 92% had a rescue medication, and 2% reported no medication. An additional 2% reported medication availability but could not recall the name and hence could not be classified. Albuterol inhaler was the most commonly reported medication (81%).

Parental Perception of Asthma Control

Only 20% of respondents indicated that the child's asthma was "poorly" controlled or "somewhat" controlled during the previous 4 weeks. Forty-one percent indicated "well" and 39% "completely" controlled asthma. Nearly all parents indicated that they were "very" (67%) or "mostly" (23%) confident in their ability to control their child's asthma.

Relation Between Outcomes and Perceived Control

To assess how the outcomes (symptoms, school absenteeism, activity limitations, and use of health services) compared with parental perception of asthma control, perceived control was sorted into 2 groups: "well controlled" (including "completely" or "well" controlled) and "poorly controlled" (including "somewhat," "poorly," and/or "not at all" controlled). Chi-square comparisons across these dichotomous groups revealed differences in health service use, school absences, activity limitations, presence of symptoms, and use of rescue medications (Table 1). Between-group comparisons revealed statistically

Table 1
Analyses Comparing Parental Perception of Control vs. Reported Asthma Outcomes

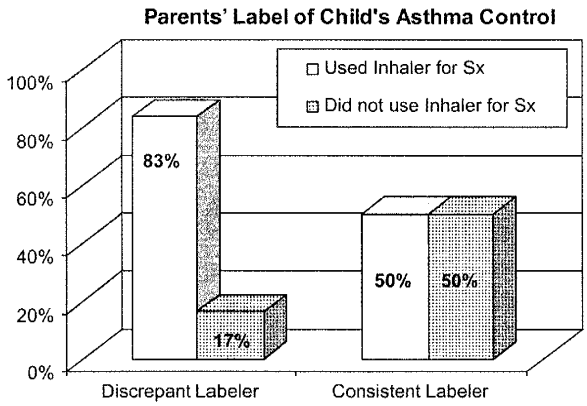
	Parental Perception of Control	
Survey Item	**Well (N = 285) n (%)**	**Poorly (N = 70) n (%)**
In past year, due to asthma child was hospitalized	15 (5.5)	9 (13.2)
in Emergency Department (ED)	66 (24.0)	24 (35.3)*
visited provider (unscheduled)	105 (38.2)	38 (55.9)*
missed school	134 (48.7)	50 (73.5)*
limited participation in exercise, sports, or recreation	112 (40.9)	36 (52.9)*
In past 4 weeks, due to asthma child		
experienced asthma symptoms	138 (50.2)	61 (89.7)*
awakened in the night	79 (2.2)	42 (61.8)*
used inhaler for symptoms	154 (56.4)	60 (88.2)*

* $p < .05$ (chi-square).

significant ($p < .05$) associations between perceived control and asthma morbidity for all outcomes except "hospitalization in the past year." The children whose parents indicated that they were poorly controlled had significantly higher rates of health service use, absences, activity limitations, and use of rescue inhaler. Of note, a relatively large number of parents (n = 138; 40%) reported well- or completely controlled asthma despite the use of health services, rescue medications, absenteeism, or presence of symptoms. This result is consistent with our hypothesis that there would be differences between what parents considered to be adequate control vs. what health professionals mean by control.

To better understand this discrepancy, these dichotomous groups were regrouped based on whether their report of the child's *control* in the past 4 weeks was in accord with their report of the child's *symptoms* in the past 4 weeks. Those parents whose report of control and report of symptoms were in agreement were categorized as "consistent" labelers. Those parents who labeled the child in good control in the presence of symptoms and those parents who labeled their child as poorly controlled in the absence of symptoms were considered "discrepant." One hundred ninety-six parents (58%) were categorized as "consistent" labelers and 145 (42%) as "discrepant." A reliability test (kappa statistic) showed statistically significant low reliability for the agreement between perceived control and "use of inhaler for symptoms" among the discrepant labelers (kappa = 0.35; $p < .05$). More importantly, use of an inhaler for symptoms was reported by 83% of discrepant labelers compared with only 50% of consistent labelers (Figure 1) (relative risk = 2.8, confidence interval [95%]: 1.5-4.1]). Only those parents who reported having a rescue medication were included in this analysis (n = 325). Discrepant labelers were nearly 3 times as likely to report having used a rescue medication than were consistent labelers.

Figure 1
Parental Labels of Asthma Control and Child's Use of Inhaler for Symptoms (N = 325)



Consistent: child's asthma control noted as complete/well controlled in presence of symptoms or noted as poor/not controlled in absence of symptoms (N = 186 or 57% of total parents)
Discrepant: child's asthma control noted as complete/well controlled in absence of symptoms or noted as poor/not controlled in presence of symptoms (N = 139 or 43% of total parents), $p < .05$.
Parents who did not report having a rescue medication (n = 32) were eliminated from this analysis.

DISCUSSION

In this sample of over 300 school-aged children with asthma, many parents reported good asthma control, but only 58% of parents' responses were consistent between their assessment of control and the reported symptoms. These findings identify a potentially high-risk group for asthma morbidity: children with "out of control" asthma perceived as well controlled by parents. Our results are consistent with the world literature on perceived control and severity of asthma[6] but are nevertheless surprising to most health care personnel and have been useful for planning community interventions for asthma.[7] One explanation of this discrepancy may be that use of a rescue inhaler (eg, albuterol) for symptoms indicates poor control clinically, but from a parent's perspective being able to reduce symptoms when they appear (through rescue inhaler use) may be viewed as "controlling" asthma.

There are limitations to this study. Our results (based on symptoms only during the prior 4 weeks) may be conservative and may overestimate chronic control. Data are self-reported among this randomly selected sample. Despite anonymity, responses may be affected by social desirability. Although contact attempts occurred on different days and times, these respondents may not represent the general population from which they were drawn. Furthermore, they may not represent the overall parental population with school-aged children. These limitations may affect generalizability; however, the levels of poor control were generally consistent with the national literature, suggesting that the sample is representative.[6,8]

CONCLUSIONS

We found a significant discrepancy between parental perceptions of their children's asthma control and their reports of asthma morbidity and found that children with out of control asthma perceived as "well controlled" by parents are at particularly high risk for asthma morbidity. These results imply that asthma morbidity could be significantly reduced by efforts to improve community-level understanding about maintenance of full function with chronic asthma control (as opposed to acute treatment of symptoms). We expect a future follow-up survey to reveal an increase in the percentage of symptom-free children. ■

References

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What is Asthma Control?
Discrepancies Between Parents' Perceptions and Official Definitions

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Earn .5 CECH Category I CHES, OH0005
Earn .6 Continuing Nursing Education Contact Hours

1. The NAEPP guidelines define asthma control as:
   a) Successful treatment of exacerbations by healthcare professions.
   b) Prevention of symptoms.
   c) Use of Albuterol for home management of symptoms.
   d) No unnecessary provider appointments.

2. Which of the following **WAS NOT** used as an outcome measure in this study?
   a) Use of inhaler.
   b) Parental perception of asthma control.
   c) Presence of symptoms.
   d) Activity limitations.

3. In this study, what percentage of parents reported well or completely controlled asthma even though the child experienced health services use, rescue medication use, absenteeism or the presence of symptoms?
   a) 23%.
   b) 30%.
   c) 40%.
   d) 75%.

4. What is a limitation of this study?
   a) Random selection of households.
   b) Comparability with national statistics.
   c) Anonymity of respondents.
   d) Reliance on self-report.

5. Because many parents do not think their child's asthma is out of control despite the child's having frequent asthma attacks, community-level education needs to emphasize:
   a) Treatment of symptoms.
   b) The newest medication available.
   c) Improved understanding of full function with chronic asthma control.
   d) Definition of severity levels.

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Answer Sheet (Event 01008)

1. A ☐ B ☐ C ☐ D ☐
2. A ☐ B ☐ C ☐ D ☐
3. A ☐ B ☐ C ☐ D ☐
4. A ☐ B ☐ C ☐ D ☐
5. A ☐ B ☐ C ☐ D ☐

❑ **.5 CECH Category I CHES, OH0005** ❑ **.6 Continuing Nursing Education Contact Hours**

Instructions

- Select the answer and check the corresponding box on the Answer Sheet. Retain the test questions as your record.
- Complete the Registration, Evaluation, and Payment Information in the space provided.
- Return the Answer Sheet to: Continuing Education Coordinator, American School Health Association, 7263 State Route 43, PO Box 708, Kent, OH 44240; 330/678-4526 (fax).
- 80% constitutes a passing score.
- Please allow 4-6 weeks for processing. For recertification purposes, the date that contact hours are awarded will reflect the date of processing.

Objectives

Learners should be able to: 1) Describe the research or case study; 2) Identify lessons learned from that study; 3) Determine whether the lessons learned apply to their practice; 4) Utilize relevant lessons learned to improve their practice. (Event 01008)

Evaluation *(please circle rating)*

1) The stated objectives were met.	Disagree	1	2	3	4	5	Agree
2) The content was related to the objectives.	Disagree	1	2	3	4	5	Agree
3) The content was clearly written.	Disagree	1	2	3	4	5	Agree
4) The test questions were clearly written.	Disagree	1	2	3	4	5	Agree
5) The content was related to my practice needs.	Disagree	1	2	3	4	5	Agree
6) The module was easy to access and use.	Disagree	1	2	3	4	5	Agree

7) Time it took to review the module and take the test: ____ minutes.

Send comments to: Mary Bamer Ramsier, PO Box 708, Kent, OH 44240; mbramsier@ashaweb.org

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